

Changes in life - being a patient

- Born 1948
- MD 1972
- Prof. of medicine 1984
- Research focus: viral hepatitis, liver failure, genetic liver diseases

- 5 operations before 2002, (including knee surgery after a skiing accident) otherwise no major health problems
- Lifelong fight with overweight (always losing..)

After 2002

- Two “independent” problems
- Liver (my area of expertise)
- Orthopedic traumatologic problems (no knowledge)

Annus horribilis - 2003

Disease

- Routine health check – chronic hepatitis C cirrhosis – thrombopenia, low albumin

Plans

- Applying for department chief in a major hospital in Vienna (listed as #1)
- Invited speaker:
 - EASL Geneva
 - Panamerican GI meeting in Punta del Este
- Scientific chairman UEGW

Annus horribilis - 2003

Disease

- Routine health check – chronic hepatitis C cirrhosis – thrombopenia, low albumin
- Start with PEGIFN/RBV 3/2003, poorly tolerated*
- Anuria, kidney failure
- Admitted to ICU

Plans

- Applying for department chief in a major hospital in Vienna (listed as #1)
- Invited speaker
 - EASL Geneva
 - Panamerican GI meeting in Punta del Este
- Scientific chairman UEGW

* Contraindicated according package insert

Annus horribilis - 2003

Disease

- Admitted to ICU multiorgan failure (6/03, 6 weeks):
 - Artificial ventilation
 - Hemofiltration
 - Hemodialysis
 - Pericardial catheter
 - Paracentesis, Pleura puncture
 - Multiple antibiotics
- SURVIVED!

Plans

Annus horribilis - 2003

Disease

- SURVIVED!
- Rehabilitation 3 weeks
- Restart working Sept. 2003

Plans

- Applying for department chief in a major hospital in Vienna (listed as #1)
withdrawn
- Invited speaker
 - EASL Geneva **replaced**
 - Panamerican GI meeting in Punta del Este
- Scientific chairman UEGW

Annus horribilis - 2003

Disease

- SURVIVED!
- Rehabilitation 3 weeks
- Restart working Sept. 2003

Plans

- Invited speaker
 - Panamerican GI meeting in Punta del Este
 - Traveled to Uruguay (9/03), postcongress tour to Brazil
 - Second trip to Brazil, then to Boston (AASLD)
- Scientific chairman UEGW
 - Prepared program in Brazil
 - Presented to scientific committee in Madrid (11/03)
 - Heavy criticism for delayed presentation
 - Resigned as chairman

What did I learn

- Doctors are anxious to treat their college, especially if he knows more about the disease than they do. Decisions are delayed or not enforced.
- As consequence I did not trust all of my colleges, (only sometimes). Followed my own expertise
- Own family (3 physicians) and nursing staff most helpful
- Keep going – best way to recovery

- So, I was a very difficult patient!

Annus horribilis - 2005

Disease

- Bike accident in April with compression fracture of the left knee, no surgery, light cast for 10 weeks
- Rehabilitation in the hospital

Plans

- Family
 - Wedding of my daughter
- Invited speaker
 - APASL Bali
 - Liver meeting in Australia
 - WCOG Montreal

Annus horribilis - 2005

Disease

- Suspicion of HCC, on the day of US guided biopsy I slipped after underwater therapy, fracture of the left patella
- oLTX 13/7/2005, uneventful recovery
- Restart working Oct. 2003

Plans

- Invited speaker
 - APASL Bali
 - Liver meeting in Australia
 - WCOG Montreal (**cancelled**)

My trip to Bali and Australia

- Everybody thought I am crazy, except for my surgeon
- His advice: if your urine gets dark, increase the dose of immunosuppression, if you start having tremor, decrease it

My trip to Bali and Australia

- Everybody thought I am crazy, except for my surgeon (postop. day 28)
- His advice: if your urine gets dark, increase the dose of immunosuppression, if you start having tremor, decrease it
My son and my daughter accompanied me

Annus horribilis - 2007

- Spontaneous fracture of the left hip (Nara, Japan) – 2/07
- Total endoprosthesis left hip in Vienna
- Endoprosthesis left knee 8/07



Annus horribilis - 2007

Disease

- Spontaneous fracture of the left hip (Nara, Japan) – 2/07
- Total endoprosthesis left hip in Vienna
- Endoprosthesis left knee 8/07

Plans

- Invited speaker
 - APASL Kyoto 3/07
 - Liver meeting in Australia

- Everybody thought I am crazy
- The surgeon strongly advised to go to a rehab camp
- But: I need crutches in Vienna, it is not different in Australia and the South Pacific

My experience with traumatologist

- They do not care about your wishes (even in the selection of the surgeon)
- They are sometimes brutal
- 2 traumatologists have 4 opinions!

My experience with not involved physicians (“colleagues”)

- They are curious and happy to spread the news
- Most do not care (see my experience as UEGW chairman) or are even unfriendly

(My) Strategies to cope with a serious, life threatening disease

- **Be informed**
 - very special situation: expert hepatologist with liver failure
 - Whom should I trust?
 - Base decisions on my experience + the advise of doctors I trusted
- **React:**
 - Fight anxiety and depression
 - Be active to improve the situation
- **Think always positive** on the future (not just on death!)

My life after 2007

- I am still active
- Wrote > 150 papers incl. 5 in the NEJM
- Travel a lot (100,000-150,000 miles/year)
- Have 4 grandchildren, very enjoyable!
- My knee still hurts and I am still obese

Summary

- An expert physician is a difficult patient, it is much easier to deal with patients who are not so well informed
- Each patient deserves an individual approach, this is not provided by guidelines or EBM, only by appropriate training
- My history is not to be generalized – I successfully avoided any changes in life, if possible



- **Authors interviewed sick physicians after they returned to work, 19 of 77 selected participated**

- Key findings

- Illness, surprising to many doctors, forces an entire reappraisal of their view of the world and their place within it.
- Many doctors internalise the perceived negative responses of colleagues and others to their illness.
- These factors contribute to the difficulties faced by doctors in returning to work.

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Der Arzt – ein ungeliebter Patient (the physician - the unliked patient) Ripke, 1999

- **More a cotreater than a patient**
- **Speaks about mistakes of colleges**
 - Their poor history taking
 - Their poor explanations (the patient is physician, he/she should know it)
 - Their anxiety to treat a college
 - Their anxiety to reveal a lack of knowledge
- **Becoming sick is a self inflicted condition?**

Strategies to cope with a serious, life threatening disease

- **Be informed**
 - very special situation: expert hepatologist with liver failure
 - Whom should I trust?
- Decisions are based not on individual need but on “guidelines” and EBM
 - Guidelines are a compromise (useless for individual patients)
 - EBM – useless and dangerous tool invented by big pharma and insurance companies, it will kill the “art of healing”